

Beneath the Mask

Evaluation of
Leading the Way
Support Program
(1998-2006)

Toronto, Canada



**The
Teresa
Group**



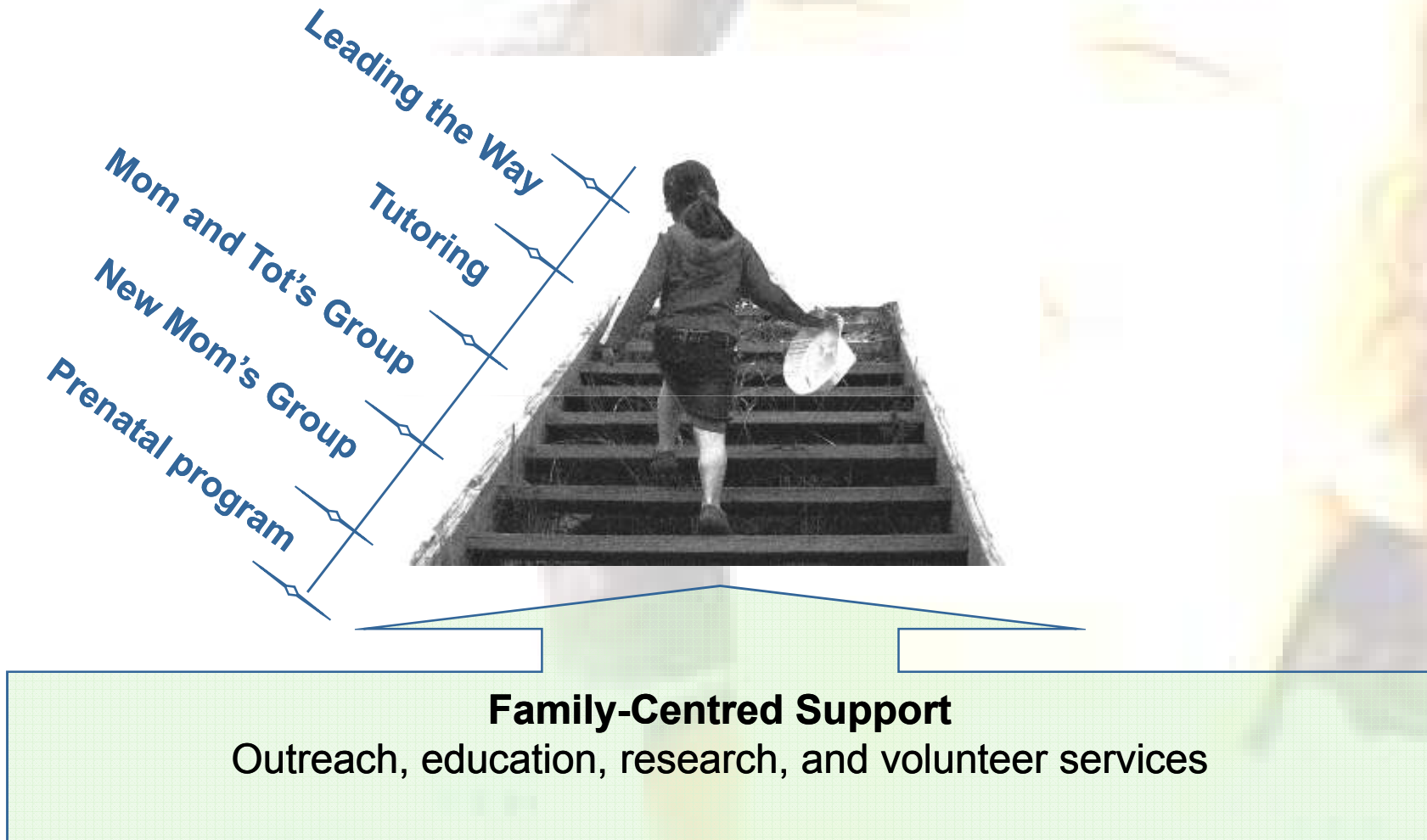
...hearing the voices of children

Beneath the Mask

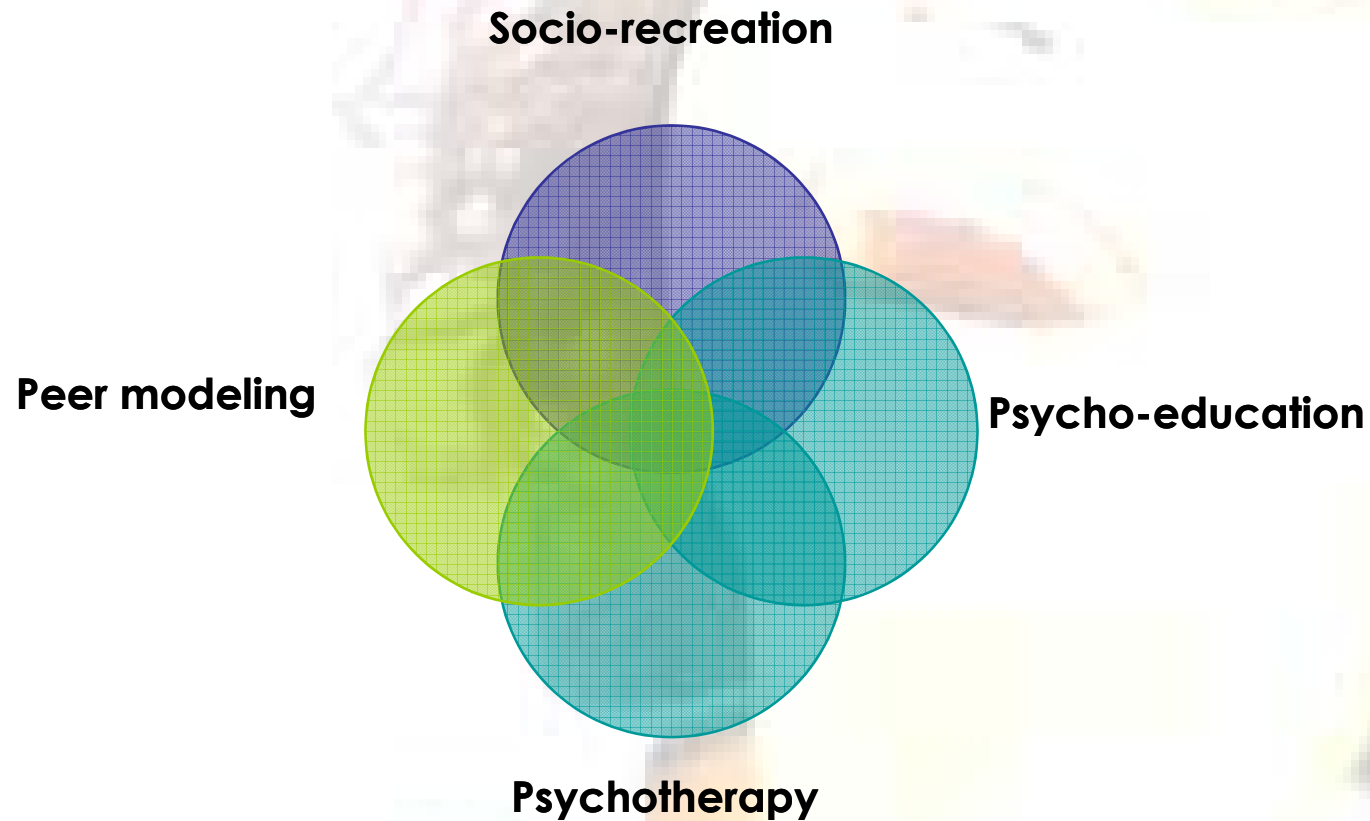
“It’s [like] wearing a mask on top of a mask, and you can never take it off because you are so used to hiding things...”

- To what extent do children affected by HIV/AIDS experience heightened levels of anxiety and depression?
- What is the impact of the Leading the Way program on children/youth infected or affected by HIV/AIDS?
- What best practices can be identified from the LTW program?
- What challenges need to be addressed in order to better support LTW children?

A Continuum of Support: The Teresa Group Programs

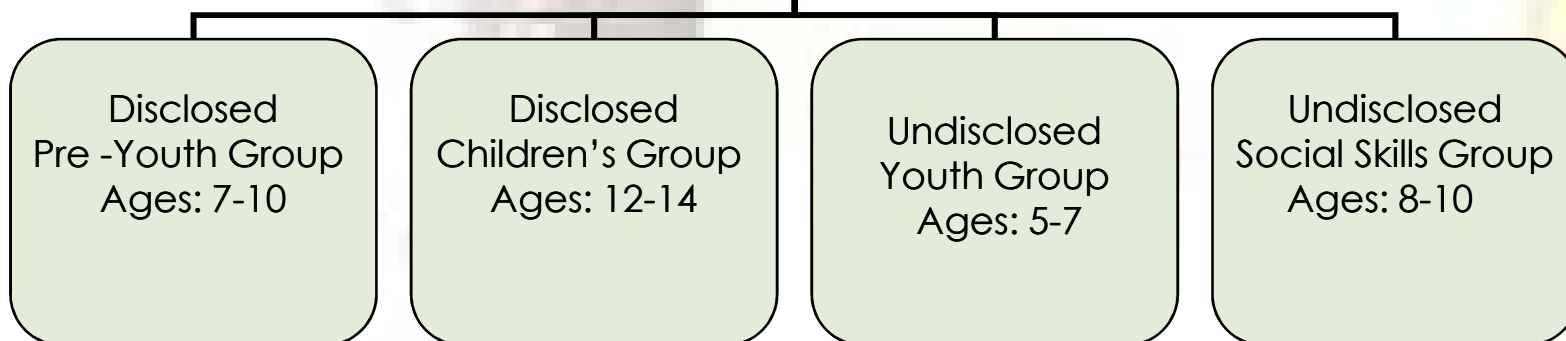


Leading the Way Approach **Activity-Centred Therapy**



Leading the Way

Spring 2007 Group Structure

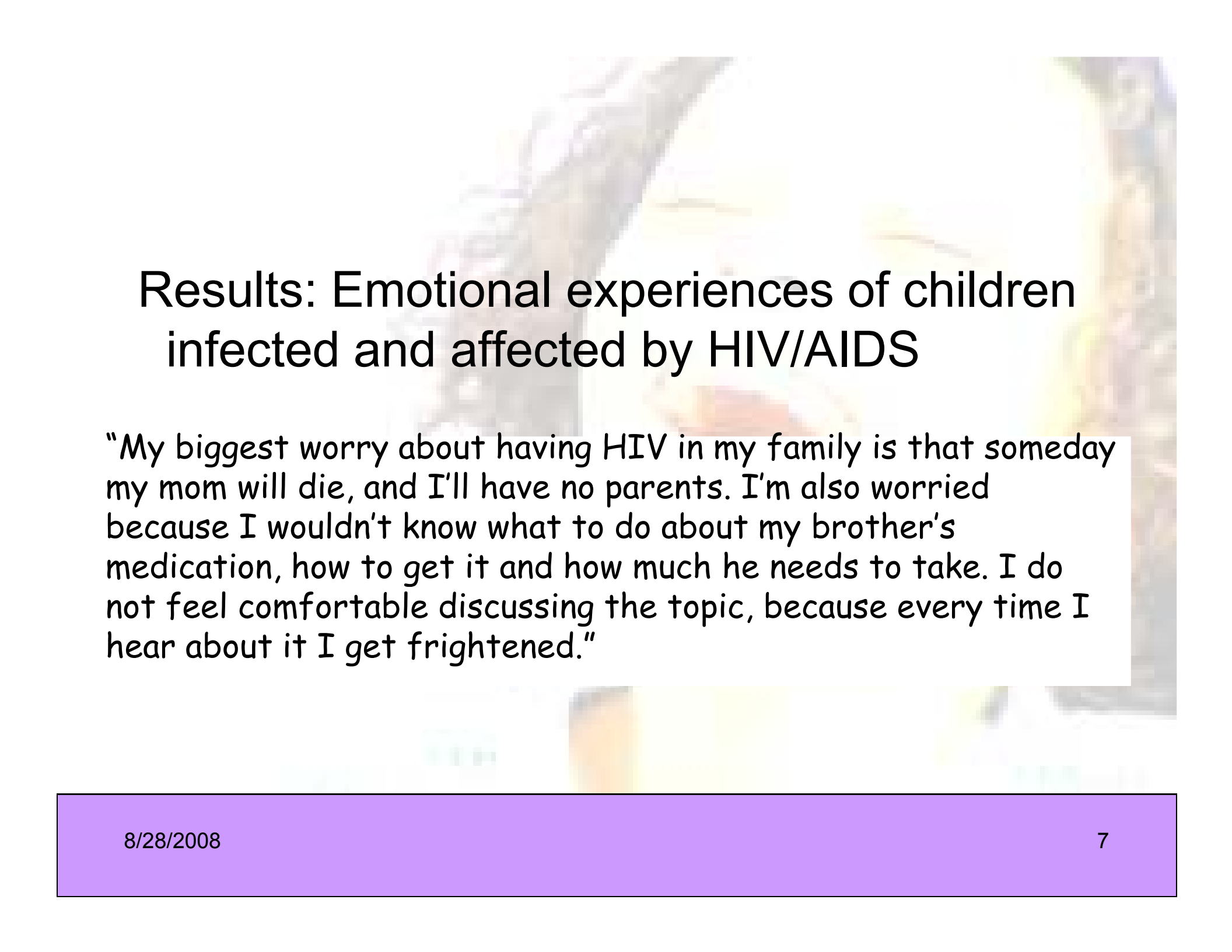


Disclosed - Children who **know** the HIV/AIDS in the family

Undisclosed - Children who **do not know** the HIV/AIDS status in the family

Qualitative and Quantitative Data

- **Child Depression Inventory** (2002–2006)
- **Revised Children's Manifest Anxiety Scale** (2002–2006)
- **Participant Pre and Post Surveys** (2004–2006)
- **Retention rate** (1999–2006)
- **Facilitator Group and Individual Reports** (1998–2006)
- **Visual and audio data** (2004–2006)

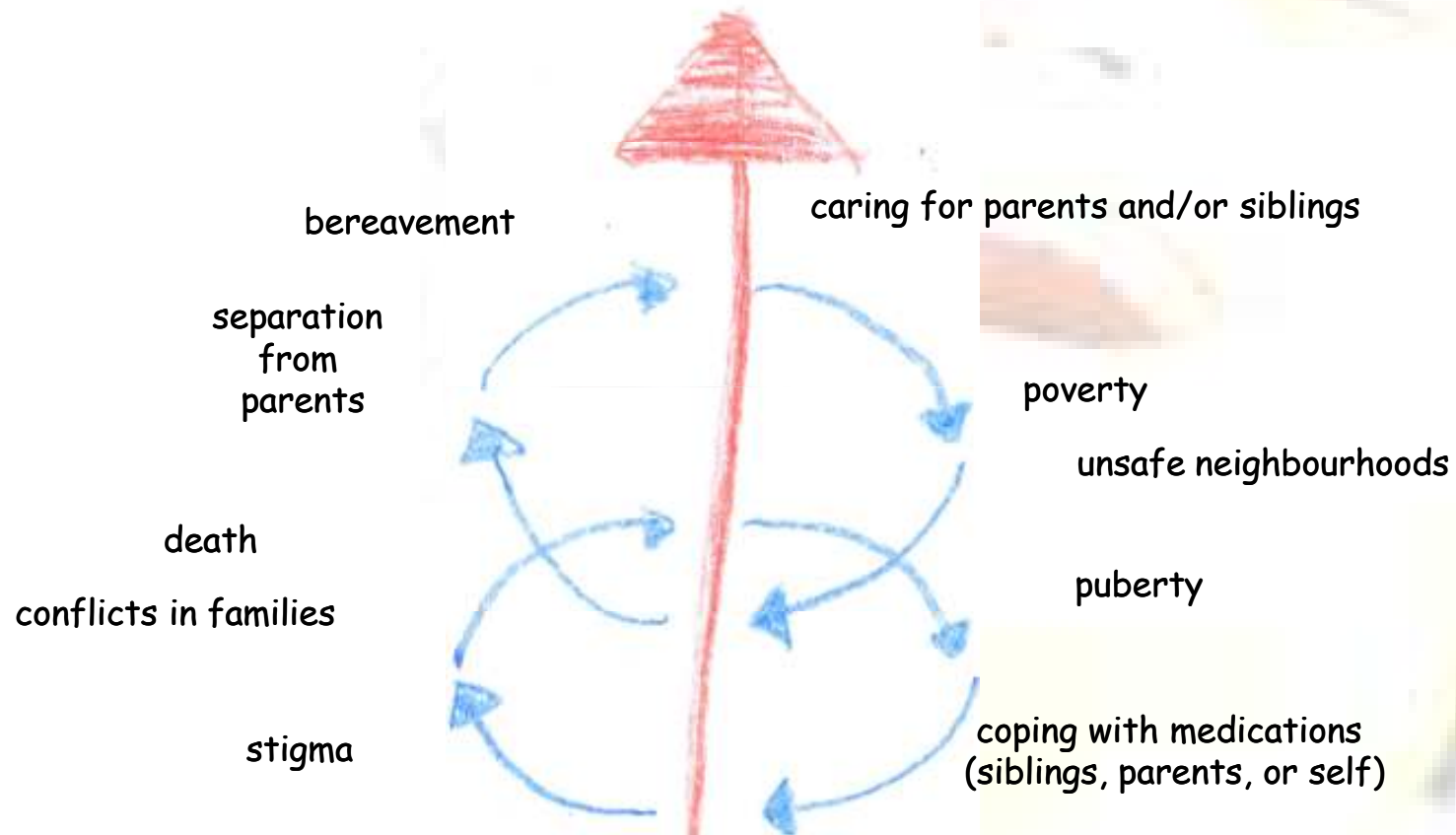


Results: Emotional experiences of children infected and affected by HIV/AIDS

"My biggest worry about having HIV in my family is that someday my mom will die, and I'll have no parents. I'm also worried because I wouldn't know what to do about my brother's medication, how to get it and how much he needs to take. I do not feel comfortable discussing the topic, because every time I hear about it I get frightened."

Results

Need for regular and ongoing support vs. onetime interventions



Results

Impact of secrecy and isolation

"HIV/AIDS=
Horrible, Invisible,
Very worried,
Arguments, Death,
Scared."

"A man would throw a woman out if he found out she had HIV. He would throw her in the trash can. 'You're too dirty for me, get out of my life.'"

"Paradise is a place where you can stomp your feet and yell, a place we can go to sleep and forget why we are mad."

"I know it is wrong to be angry."

Results

Higher levels of depression than norm

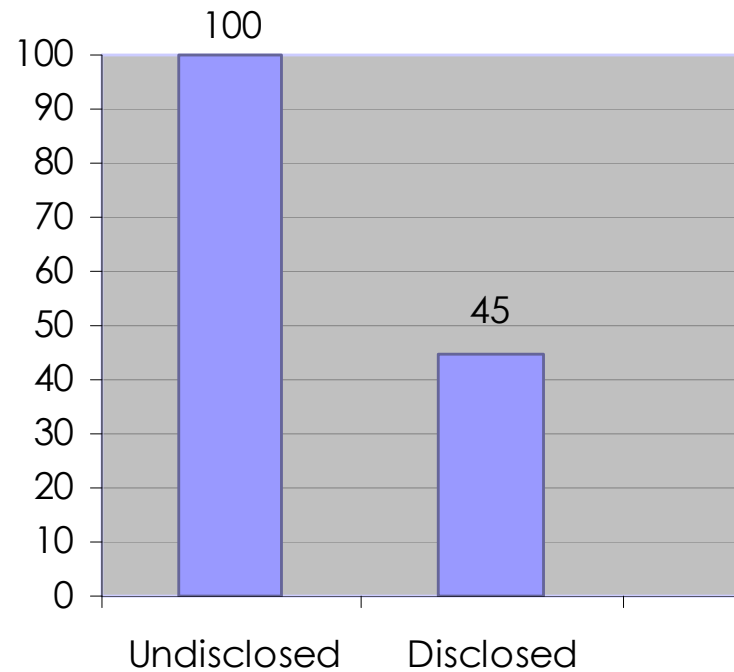
60% of the children at LTW score above the 50th percentile for depression

15% of LTW participants scored about the 80th percentile

Results

Children who are **unaware** of HIV in their families experience higher levels of depression

% of children above 50th percentile-depression



2. Impact of Leading the Way



Results

Relationship between time in program and CDI and RCMAS scores

Participation in LTW correlates to a decrease in anxiety.

68% of children reported decrease of anxiety after participation in one or more sessions.

Participating children showed a decrease in depression over time.

76% of children who had participated from six months to four years showed a decrease in their depression scores over time.

Results

Children gain skills to cope with HIV/AIDS and other life events

Improved ability to cope through different stages:

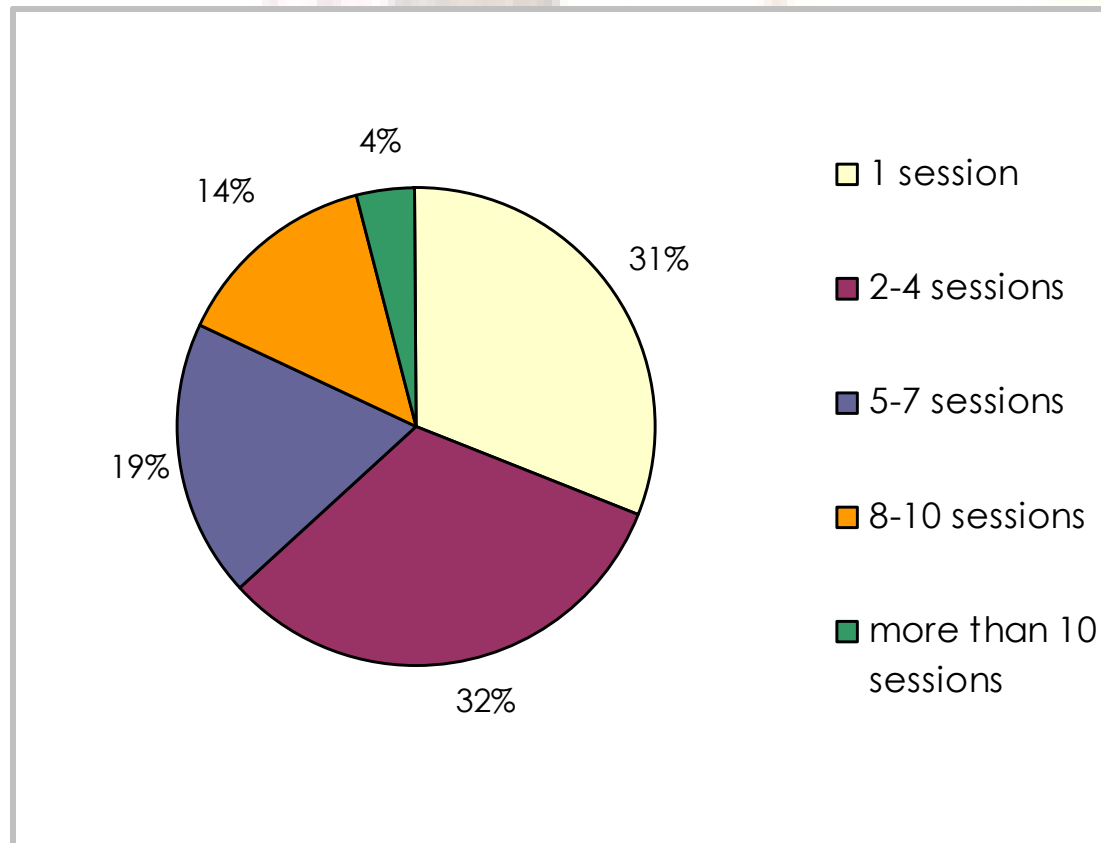
normalizing feelings; expressing feelings; accepting the situation, identifying strategies for coping

Improved self-esteem through skill-building activities

"I learned that while dancing if you mess it up you keep going and I guess you can use that in life too."

Results

High retention rate: almost 70% of participants return after one session



Results

Improved ability to express hope and motivate others



"HIV/AIDS=Happy
Inspired
Versatile/Awesome
Independent
Distinct Special"

Results

Children want and need different avenues for expression and learning: **“to speak sideways”**



“I got to talk about HIV/AIDS from a different perspective.”

Results

Children experience a strong sense of support at LTW

“I have the feeling that I am not alone.”

“It’s a good way to talk about the topic without feeling different, because we are all around the same age and experience the same problems in life.”

Promising Practices

- Multiple and creative avenues of expression
- Strengths-based approach effective for building resiliency
- Flexible approach through children's participation and structured debriefing
- “Continuum of care” and holistic approach

Future Directions



- Increased involvement of children in “speaking back”
- Strengthened support for families during the disclosure process
- Strengthening community support: focus on education and sensitization of front line workers